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How Neuroscience Technology Is Changing Our Understanding of Brain Injury, Vegetative States and the Law

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HOW NEUROSCIENCE TECHNOLOGY IS CHANGING OUR UNDERSTANDING OF BRAIN INJURY, VEGETATIVE STATES AND THE LAW

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The author examines clinical studies that use neuroscience technology to study patients in Vegetative States. The studies indicate that some of the patients are, in fact, conscious. The author suggests that this finding is a matter of considerable practical importance for the drafting and execution of end-of-life protocols such as Advance Directives and Living Wills. He recommends that statutes, and other guidance used by patients, caregivers, medical institutions, family members and others to draft and interpret such Directives and Wills, be revised or amended to take account of these results.

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I. INTRODUCTION

Imagine a car crash, a violent one. There are fatalities. The survivors all have badly broken bodies, and your loved one, Lucky, is among them. She is alive but unconscious. After a month, Lucky still has not regained consciousness, so the attending physician puts Lucky in the category "persistent vegetative state." In this category, a patient is regarded, in effect, as a kind of human potato, a living body with no mind and no experience of consciousness. After a year without improvement, Lucky is further downgraded to the category "permanent vegetative state." At this point, the physician, acting in accordance with methods and theories generally accepted by the medical science community, has determined there is virtually no chance that Lucky will ever regain consciousness.

That determination has profound personal consequences for Lucky and her loved ones, of course, but can have profound legal consequences as well. In particular, it can trigger a provision in an Advance Directive, a legally binding instrument signed by Lucky. That provision instructs Lucky's medical caregivers, upon determining that she is in a permanent vegetative state, to disconnect her from life support devices. As a result, she will expire. That outcome would be consistent with Lucky's intentions and wishes when originally signing the Advance Directive—the point was, after

all, to ensure her something like "death with dignity"[1] rather than life as a mindless organism attached indefinitely to electrodes, hoses, and machines. Lucky might have expressed the idea like this:

> Well, if the doctor thinks I've been hurt so badly that I've turned into a turnip or a carrot, with pretty much no chance of waking up or getting back to normal, let's just pull the plug then, and get it over with. I don't want to live that way . . . that really isn't living. Besides I don't want to be a bother or an expense for anyone else.

As we shall see in the data presented below, this tragic circumstance is not a particularly exotic one in the healthcare world. Moreover, the reasoning that drives the decision-making process used by Lucky and others when signing the Directive seems sound and appealing, however grim the subject matter.

Having reached the "point of no return" where experts advise that we will almost certainly never regain consciousness, many of us would opt, if we had a chance to plan, for a "death with dignity" scenario and would execute an Advance Directive. But here's the rub. What if Lucky is *not actually beyond the point of no return*, but you don't know it, and Lucky's physician doesn't know it? Would we want the plug to be pulled in such a circumstance? To be blunt, that was *not* Lucky's intention or wish when signing the Directive. A well-informed and benevolent observer might ask those who are about to pull the proverbial plug: (a) whether and how new developments at the frontiers of neuroscience might matter for Lucky and others who are similarly situated, and (b) whether those developments should compel changes in laws, regulations, guidelines, and the actions of caregivers concerned with Advance Directives, brain injury, and vegetative states.

In what follows, we will step into the shoes of such a benevolent observer. Among our central questions will be these: can patients in vegetative states nonetheless be conscious?[2] And, if so, can

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[1] *See, e.g.*, TIMOTHY E. QUILL, DEATH AND DIGNITY: MAKING CHOICES AND TAKING CHARGE (1994).

[2] Bryan Jennett and Fred Plum are credited with introducing the expression "persistent vegetative state" in 1972. *See* Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 LANCET 734, 736 (1972). See *infra* discussion accompanying note 7, for the

advanced neuroscience technology reveal the existence of consciousness and conventional mental states in such patients despite all other conventional indications to the contrary? We will see that for some patients, at least, the surprising answer to these questions is "yes." Recent research with PVS patients has made effective use of neuroscience technology, such as Functional Magnetic Resonance Imaging ("fMRI") machines and other tools,[3] and produced quite promising insights into these difficult and sensitive matters.[4] In fact, it would not be an exaggeration to say that some of the research has produced powerful evidence that certain PVS patients are conscious and possess significant cognitive ability.[5] The consequences are far reaching for patients and loved ones and for the law of Advance Directives and end of life protocols as well.

Below, we describe in Section II the basics of persistent and permanent vegetative states ("PVS") and review what I call the traditional clinical account ("Traditional Account")[6] and its approach to consciousness, mental states and behavior in PVS

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difference between "permanent" and "persistent" vegetative states, and other conditions.

[3] For example, Positron Emission Tomography ("PET"), Computed Tomography ("CT"), Electro-encephalography ("EEG"), and Single Photon Emission Computed Tomography ("SPECT"). *See generally* Marcus E. Raichle, *A Brief History of Human Brain Mapping*, 32 TRENDS IN NEUROSCIENCES 118 (2008) (containing an informative historical review of these technologies).

[4] *See, e.g.*, Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 585–89 (2010) (using fMRI to support awareness in a vegetative or minimally conscious state).

[5] *Id.* But see P. Nachev & P.M.S. Hacker, *Covert Cognition in the Persistent Vegetative States*, 91 PROGRESS NEUROBIOLOGY 68, 68 (2010), for a critical perspective.

[6] *See generally* Multi-Soc'y Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (First of Two Parts)*, 330 NEW ENG. J. MED. 1499 (1994) [hereinafter MSTF I]; Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (Second of Two Parts)*, 330 NEW ENG. J. MED. 1572 (1994) [hereinafter MSTF II]. Many professional groups participated in the task-force, including the American Neurological Association, the American Academy of Neurology, the Child Neurology Society, the American Academy of Pediatrics, and the American Association of Neurological Surgeons.

patients and others who have suffered serious brain injury.[7] We then discuss, in Sections III and IV, recent research with PVS patients, the nature of the diagnostic challenge facing clinicians, and data on misdiagnosis. Finally, we review in Section V legal descriptions of PVS in current state guidelines, statutes and other materials, which are used to shape Advance Directives and "living wills,"[8] and to educate patients, family members, and caregivers. We conclude with recommendations for law makers, regulators, and health-care professionals who care for brain injured patients on a daily basis.

II. BACKGROUND

A. *The Phenomenon*

In their 2005 paper, Beaumont and Kenealy estimated that the occurrence of PVS cases enduring for six months or more is between 5 and 25 per million in the United Kingdom, and between 40 and 168 per million in the United States.[9] As such numbers suggest, the average person is unlikely to fall victim to PVS or encounter it among relatives or friends. From time to time, certain cases have captured public attention in the popular press because they have been politically or ethically controversial, or notable for other

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[7] *See generally* JAMES L. BERNAT, ETHICAL ISSUES IN NEUROLOGY 283–305 (2nd ed. 2002); BRITISH MEDIC. ASS'N, BMA GUIDELINES ON TREATMENT DECISIONS FOR PATIENTS IN PERSISTENT VEGETATIVE STATES (1996); BRYAN JENNETT, THE VEGETATIVE STATE: MEDICAL FACTS, ETHICAL AND LEGAL DILEMMAS 1–32 (2002); Megan Alcauskas, *Prognosis and Therapy After Cardiac Arrest-Induced Coma*, 11 AMA J. ETHICS 617 (2009) (defining and distinguishing consciousness and coma); Quality Standards Subcomm., Am. Acad. Neurology, *Practice Parameters: Assessment and Management of Patients in the Persistent Vegetative State*, 45 NEUROLOGY 1015 (1995) (responding to MSTF I and MSTF II); Adam Zeman, *Persistent Vegetative State*, 350 LANCET 795 (1997) (placing "PVS in the context of current understanding" of recent findings in the field).

[8] Luis Kutner, *Due Process of Euthanasia: The Living Will, a Proposal*, 44 IND. L.J. 539, 551 (1969).

[9] J. Graham Beaumont & Pamela M. Kenealy, *Incidence and Prevalence of the Vegetative and Minimally Conscious States*, 15 NEUROPSYCHOLOGICAL REHABILITATION 184, 188 (2005). Data collection is somewhat hampered by the hazards of misdiagnosis. It seems even in industrialized countries, cases may be under-reported because they develop in nursing homes, assisted living facilities or private residences rather than hospitals.

reasons. Among those that have received considerable attention in recent years have been the cases of Theresa Schiavo,[10] Sunny von Bülow,[11] Karen Ann Quinlan,[12] Nancy Beth Cruzan,[13] and Ariel Sharon, the former Prime Minister of Israel.[14]

According to the Traditional Account and similar characterizations, the PVS patient typically presents with cycles of sleep and wakefulness, and may have open eyes. But the patient seems not to have what physicians call awareness, or what the average person might call consciousness.[15] Using a biomedical idiom, one might say the physician believes the patient to have no awareness of self or environment. Alternatively, in more vernacular speech, one might say the physician believes the patient to have *a complete lack of consciousness*. When physically examined, the patient shows "no evidence of language comprehension or expression" and "no evidence of sustained, reproducible,

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[10] *In re* Guardianship of Schiavo, 916 So. 2d 814 (Fla. Dist. Ct. App. 2005); *In re* Guardianship of Schiavo, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001); Abby Goodnough, *Schiavo Dies, Ending Bitter Case Over Feeding Tube*, N.Y. TIMES (Apr. 1, 2005), https://www.nytimes.com/2005/04/01/us/schiavo-dies-ending-bitter-case-over-feeding-tube.html.

[11] State v. von Bülow, 475 A.2d 995 (R.I. 1984), *cert. denied*, 469 U.S. 875 (1984); Enid Nemy, *Sunny von Bülow, 76, Focus of Society Drama, Dies*, N.Y. TIMES (Dec. 6, 2008), https://www.nytimes.com/2008/12/07/nyregion/07vonbulow.html.

[12] *In re* Quinlan, 355 A.2d 647 (1976); Robert McFadden, *Karen Ann Quinlan, 31, Dies; Focus Of '76 Right to Die Case*, N.Y. TIMES (June 12, 1985), https://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html.

[13] Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990) (affirming the Supreme Court of Missouri's finding that it was acceptable to require "clear and convincing evidence" of a patient's wishes for removal of life support); Tamar Lewin, *Nancy Cruzan Dies, Outlived by a Debate Over the Right to Die*, N.Y. TIMES (Dec. 27, 1990), https://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html.

[14] Isabel Kershner, *Sharon Brain Scan Shows Response to Stimuli*, N.Y. TIMES (Jan. 27, 2013), https://www.nytimes.com/2013/01/28/world/middleeast/ariel-sharon-brain-scan-shows-response-to-stimuli.html.

[15] Physicians also use "alertness." For convenience, I shall use "awareness" and "consciousness" interchangeably to the extent that grammar and style permit.

purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli."[16]

Among other curious aspects of the condition are that the patient is not necessarily immobile. In some cases, for example, the patient can move the trunk or limbs in what are described as "meaningless," which is to say non-intentional, ways.[17] The patient may also seem to smile, or become tearful, and may sometimes make sounds normally associated with grunting, moaning or screaming.[18] But these activities, too, are typically described as "non-intentional" or "non-purposeful" and downplayed because they may "misleadingly suggest purposeful movements."[19] After the patient presents, or seems to present, the diagnostic criteria enumerated in the Traditional Account for a period of one month, the patient will be placed in the PVS category.[20]

B. *Causal Factors*

How does PVS come about? The condition can be the result of a host of causal factors, including acute traumatic injuries, such as motor vehicle mishaps, gunshot wounds and rock climbing accidents, and non-traumatic injuries, such as suffocation, cardio-respiratory arrest, cerebral hemorrhage, cerebral infarction, and

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[16] *See* MSTF I, *supra* note 6, at 1500. The list of diagnostic criteria presented by the MSTF in the New England Journal of Medicine in 1994 is the *locus classicus*:

> The vegetative state can be diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes.

Id.

[17] *Id.*

[18] *Id.*

[19] *Id.*

[20] *Id.* at 1501.

bacterial meningitis.[21] It can also result from degenerative and metabolic disorders, such as Alzheimer's Disease, Parkinson's Disease, Creutzfeld-Jacob Disease, Pick's Disease, and Huntington's Disease, and developmental malformations, such as congenital hydrocephalus, hydranencephaly, and anencephaly.[22]

C. *Related Phenomena & Some Complexities of Recovery*

The vegetative state is similar to certain other related conditions clinicians will consider when making a differential diagnosis. These include, for example, the comatose state, the minimally conscious state, the "locked-in" state, and the brain-dead state.[23]

When a patient suffers a serious brain injury or brain-related disorder brought about by the causal factors above, the fervent hope of loved ones and caregivers is that the patient will make at least a partial, if not a full recovery. In practice, the patient may pass through one or more states along the theoretical road to possible recovery. But he or she may also get stuck, failing to progress beyond a particular state. Or the patient may simply lose the physical battle, expiring during the recovery process.

Suppose, for example, a car accident victim is found to be comatose. Unlike the PVS patient, who will undergo sleep-wake cycles and lack awareness, the comatose patient will lack *both* wakefulness and awareness, and will typically lie passive with

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[21] *Id.* at 1503–05.

[22] *Id.*; *see also* HARRISON'S PRINCIPLES OF INTERNAL MEDICINE 133–35 (Eugene Braunwald et al. eds., 15th ed. 2001).

[23] *See* Hal Blumenfeld, *The Neurological Examination of Consciousness, in* THE NEUROLOGY OF CONSCIOUSNESS: COGNITIVE NEUROSCIENCE AND NEUROPATHOLOGY 15–28 (Steven Laureys & Giulio Tononi eds., 2009); Caroline Schnakers & Steve Majerus, *Behavioral Assessment and Diagnosis of Disorders of Consciousness, in* COMA AND DISORDERS OF CONSCIOUSNESS 2–6 (Caroline Schnakers & Steven Laureys eds., 2012); *see also* PLUM AND POSNER'S DIAGNOSIS OF STUPOR AND COMA 342–86 (Jerome B. Posner et al. eds., 4th ed. 2007). For the ordinary non-expert—the proverbial man or woman in the street—the expression "comatose" is commonly used in casual conversation to capture all such conditions.

closed eyes.[24] Assuming the patient does not subsequently suffer brain death, an irreversible condition in which all voluntary and involuntary brain activity has ceased,[25] the patient may progress to a PVS condition.[26] Alternatively, the patient may progress to a so-called "locked-in" state, and possess *both* wakefulness and awareness, while typically lacking all motor control *except* for intentional eye movement.[27] Following Jerome Posner, one might say PVS patients "look conscious but are unconscious," whereas the "locked-in" patients "look unconscious but are conscious."[28]

As we saw with Lucky, a patient who is in a persistent vegetative state and then fails to improve after one year is not realistically expected to get better.[29] Using traditional diagnostic approaches, that patient will typically be re-classified into the category of "permanent vegetative state." But the persistent vegetative state patient who *does* improve within a year may enter the category of Minimally Conscious State ("MCS").[30] While MCS patients may be regarded as having severely altered consciousness, they present behavior that suggests to clinicians an awareness of self or

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[24] *See* MSTF I, *supra* note 6, at 1501 (explaining that awareness and wakefulness are the two states that determine consciousness, and that lacking either indicates medical unconsciousness).

[25] When properly confirmed by physicians, brain death, unlike PVS, can serve as the basis of a legal declaration of death. UNIF. DETERMINATION OF DEATH ACT § 1 (UNIF. LAW COMM'N 1981).

[26] MSTF I, *supra* note 6, at 1502–03.

[27] *Id.* In the more extreme variant, the locked-in patient lacks motor control of the eyes as well. *See* G. Bauer et al., *Varieties of the Locked-in Syndrome*, 221 J. NEUROLOGY 77, 84–85 (1979); Steven Laureys et al., *The Locked-in Syndrome: What is it Like to be Conscious but Paralyzed and Voiceless?, in* SER. NO. 150, PROGRESS IN BRAIN RESEARCH 495, 501 (Steven Laureys ed., 2005) (noting in some cases, the eyelids may need to be manually opened to verify eye movements).

[28] Lawrence K. Altman, *Fred Plum, Neurologist Who Helped Coin 'Persistent Vegetative State,' Dies at 86*, N.Y. TIMES (June 12, 2010) (quoting Dr. Jerome Posner), https://www.nytimes.com/2010/06/13/health/13plum.html.

[29] Eelco F. M. Wijdicks & Ronald E. Cranford, *Clinical Diagnosis of Prolonged States of Impaired Consciousness in Adults*, 80 MAYO CLINIC PROC. 1037, 1044 (2005).

[30] *See* Joseph Giacino & John Whyte, *The Vegetative and Minimally Conscious States: Current Knowledge and Remaining Questions*, 20 J. HEAD TRAUMA REHABILITATION 30, 37 (2005).

environment.[31] Such behavior includes, for example, the ability to follow simple commands, to answer yes-no questions with gestures, to produce meaningful utterances, to smile or cry appropriately in response to stimuli, to move the eyes in conventional ways, and to reach for, touch and grasp objects.[32]

Occasionally, those who suffer the type of serious brain injury or disorder discussed above may experience some form of recovery, but the duration of the wait-and-see process can vary from hours to weeks to months or even years. The outcomes cannot be known in advance and can vary greatly. Two long-term cases provide stunning examples. In the first, Terry Wallis was gravely injured in an auto accident in 1984, but emerged into consciousness from PVS after 19 years in 2003.[33] In the second, Sunny von Bülow endured PVS without recovery for nearly 28 years before dying in 2008.[34]

D. *Misdiagnoses*

The physical patient behavior that clinicians study in assessing a patient may be difficult to interpret for a number of reasons: the patient may be inactive during one examination, but active during another. Or the patient's condition may improve from one day to

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[31] *See, e.g.*, *In re* Wendland, 28 P.3d 151, 154–55 (Cal. 2001). Robert Wendland entered a Minimally Conscious State after suffering a head injury in an automobile accident. *Id.* at 154. He had not completed an Advance Directive, and his spouse sought to have him removed from life support, despite his mother's wishes to the contrary. *Id.* at 155. The California Supreme Court ruled that his wife did not have the authority to refuse life support, finding that patients who are unable to make a decision for themselves should receive special protection based in constitutional rights to life and privacy. *Id.* at 159, 162–63, 175.

[32] J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 350–51 (2002); *see also* Stephen Ashwal & Ronald Cranford, *The Minimally Conscious State in Children*, 9 SEMINARS PEDIATRIC NEUROLOGY 19, 20–21(2002).

[33] *See* Suzanne Goldenberg, *Terry Talks*, GUARDIAN (July 11, 2003) https://www.theguardian.com/society/2003/jul/11/health.lifeandhealth.

[34] *See* Nemy, *supra*, note 11. Sunny von Bülow's second husband, Claus von Bülow, was suspected of trying to cause her death with an insulin overdose and was convicted of attempted murder, but the conviction was overturned on appeal, following which he was found not guilty in a second trial. For an account written by Claus von Bülow's attorney, law professor Alan Dershowitz, see ALAN M. DERSHOWITZ, REVERSAL OF FORTUNE: INSIDE THE VON BÜLOW CASE (1986).

another, though it may also move in the opposite direction, from better to worse. For these reasons, the patient's condition is something of a moving target.[35] As a result, even in optimal circumstances, the behavior may be susceptible to conflicting interpretations, and therefore vulnerable to misdiagnoses.[36] The rate of misdiagnosis in cases involving disorders of consciousness appears to be alarmingly high, perhaps on the order of 40%.[37] In the 1990s, 37% of PVS patients in one study were re-diagnosed after misdiagnosis, and in another, 43% were re-diagnosed.[38]

III. RECENT RESEARCH

Recent research sheds new light on the PVS phenomenon, and suggests the problem of misdiagnosis may be worse than previously thought. That work has involved PVS patients in various experimental settings, and the use of various neuroscientific tools and methods including fMRI, PET, SPECT, and EEG.[39]

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[35] Dr. Adrian Owen has informally reported an exemplary case: a PVS patient was participating in an fMRI experiment and showed no brain activation whatsoever, but when scanned the next day the patient showed completely normal activation. *See* Jerome Groopman, *Silent Minds: What Scanning Techniques are Revealing About Vegetative Patients*, NEW YORKER (Oct. 15, 2007), https://www.newyorker.com/magazine/2007/10/15/silent-minds.

[36] *See* Keith Andrews et al., *Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit*, 313 BMJ 13, 15 (1996). In the Nancy Jobes case, four physicians were equally divided over whether the patient was in a PVS state or a state more akin to minimal consciousness. The judge found PVS to be the proper diagnosis. As a result, the patient's feeding tube was removed and she was allowed to die in keeping with a petition filed by her husband. *In re* Jobes, 529 A.2d 434, 451–52 (N.J. 1987); Joan Beck, *Nancy Jobes: A Long Fight to End a Case of Endless Dying*, CHI. TRIB. (Aug. 10, 1987), https://www.chicagotribune.com/news/ct-xpm-1987-08-10-8702280716-story.html.

[37] *See* Adrian M. Owen et al., *Detecting Awareness in the Vegetative State*, 313 SCI. 1402, 1402 (2006) [hereinafter Owen et. al., *Detecting Awareness*]; *see also* Monti et al., *supra* note 4, at 580.

[38] Nancy L. Childs et al., *Accuracy of Diagnosis of Persistent Vegetative State*, 43 NEUROLOGY 1465, 1465–67 (1993); Andrews et al., *supra* note 36, at 13.

[39] *See* Raichle, *supra* note 3, at 118. Much of this work has been done by Adrian Owen, Steve Laureys and their colleagues at the University of Cambridge (Great Britain), the University of Liege (Belgium) and the University of Western Ontario (Canada). *See* Adrian Owen et al., *The Assessment of Conscious Awareness in the*

A. *Imagery Tasks: Tennis and Navigation*

In the stunning recent work that concerns this article,[40] researchers instructed a patient to perform certain imagery tasks while in an fMRI scanner. The patient, who had been unresponsive five months after a traffic accident, was verbally asked to *think about* playing tennis and also navigating or walking through rooms in her home.[41] In healthy subjects, one finds that specific brain areas are activated during the performance of these tasks.[42] For tennis playing, which involves motor skills, the supplemental motor cortex is typically activated, and for navigation, which concerns orientation and the recognition of places, areas such as the para-hippocampal gyrus and the visual cortex are activated.[43] The traffic accident victim showed exactly the same activations.[44] In subsequent work with a large patient group of 54, the same verbal instructions were given, and five of those experimental patients, or roughly ten percent of the group, showed activation in exactly the same areas as the healthy subjects.[45]

These results are of great interest since they appear to indicate that the patients in the subset were capable of following instructions. This is important because instructions fall within the linguistic category of commands, and the ability to carry out commands strongly suggests that the patients possess cognitive ability of some significant degree.[46]

Vegetative State, *in* THE NEUROLOGY OF CONSCIOUSNESS: COGNITIVE NEUROSCIENCE AND NEUROPATHOLOGY 163, 168 (Steven Laureys & Giulio Tononi eds., 2009) [hereinafter Owen et al., *Assessment of Conscious Awareness*]; *see also* Monti et al., *supra* note 4, at 581.

[40] The initial work was reported by Adrian Owen and his team in 2006. *See* Owen et al., *Detecting Awareness*, *supra* note 37.

[41] *Id.*

[42] *Id.*

[43] *Id.*

[44] *Id.*

[45] Four of the five were PVS patients. Monti et al., *supra* note 4, at 582–83.

[46] It is widely assumed that those *brain* activations are proxies for the neural correlates of consciousness. *See* Owen et al., *Detecting Awareness*, *supra* note 37.

B. *A Novel Way to Say "Yes" and "No"*

A key follow-up experiment measurably advanced the conceptual ball. In that case, Patient No. 23 from the tennis and navigation group was asked to communicate with the researchers using a more complex signaling system.[47] She was instructed to answer yes-no questions by making special use of the mental imagery exercise: when asked a question by a researcher, she could answer "Yes" by *thinking* of playing tennis, and "No" by *thinking* of navigating through the rooms of her home.[48] The respective fMRI activations would thus count in that context as speech acts of assent ("Yes") and dissent ("No"). The researchers then asked a series of yes-no questions to which they knew the answers ("Do you have any brothers?" or "Is your father's name Alexander?" and so on).[49] In this circumstance, the patient correctly answered five questions, but did not respond to a sixth.[50]

C. *Photographs & Sentences*

Previously, experimenters had achieved promising results when using face and sentence recognition tasks. Kate Bainbridge was a 26-year-old school teacher who entered PVS after developing flu-like symptoms and then falling into a coma.[51] The experimenter placed her in a PET scanner and projected in her visual field photographs of her family, which he alternated with images of faces

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[47] Monti et al., *supra* note 4, at 584.

[48] *Id.* at 584–85. The fMRI device measures blood flow in the brain which is represented by the so-called Blood Oxygen Level Dependent signal (often referred to by the acronym BOLD). *Id.* at 587.

[49] *Id.* at 585.

[50] *See id.* The patient did not respond at all to the sixth question for unclear reasons, though it is possible she had fallen asleep. *Id.* Some critics of these results suggest the brain may be simply responding to a familiar name by reflex. The idea is that when the name of the patient's father is mentioned in the patient's presence, her brain reacts to the wave form in a mechanical way. Researchers showed that potential "reflex" names could be inserted into other sentences that the patient would find false without generating the "reflex" response. For example, suppose the patient's father was named X, and also that the patient never owned a dog. Given those circumstances, the patient would be expected to answer "yes" when asked "Is your father's name X?" but "No" when asked "Do you have a dog named X?"

[51] David Cyranoski, *The Mind Reader*, 486 NATURE 178, 179 (2012).

that were so digitally-distorted as to be unrecognizable. Whenever the family faces appeared, her brain showed activation in the Fusiform Gyrus, which is used for the highly specialized task of face recognition, and her Fusiform activations were identical to those of healthy control subjects.[52]

In other work, experimenters shifted from visual imagery to speech sounds, but using an analogous method, exposed patients to recordings of simple sentences alternating with nonsense sounds or "noise."[53] In those cases, PVS patients showed the same fMRI activations in response to the recordings as healthy volunteers. Likewise, when ambiguous sentences were used, two PVS patients showed the very same fMRI activations—those of a brain struggling to interpret words—as those of healthy volunteers.[54]

D. *Recovering Consciousness*

Beyond devising enhancements to these basic fMRI communication systems, one would like to create increasingly sophisticated brain-machine interfaces that would make it possible for patients to engage in a greater range of expression. Such developments would allow them, as Steven Laureys puts it, "to express their feelings and thoughts, control their environment and

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[52] *See* D. K. Menon et al., *Cortical Processing in Persistent Vegetative State*, 352 LANCET 200, 200 (1998). For a discussion of the Fusiform Face Area, see generally Nancy Kanwisher et al., *The Fusiform Face Area: A Module in Human Extrastriate Cortex Specialized for Face Perception*, 17 J. NEUROSCIENCE 4302 (1997); K. M. O'Craven & N. Kanwisher, *Mental Imagery of Faces and Places Activates Corresponding Stimulus-Specific Brain Regions*, 12 J. COGNITIVE NEUROSCIENCE 1013 (2000).

[53] *See, e.g.*, Matthew H. Davis et al., *Dissociating Speech Perception and Comprehension at Reduced Levels of Awareness*, 104 PROC. NAT'L ACAD. SCI. 16032, 16032 (2007); Adrian M. Owen et al., *Residual Auditory Function in Persistent Vegetative State: A Combined PET and fMRI Study*, 15 NEUROPSYCHOLOGICAL REHABILITATION 290, 292–98 (2005).

[54] *See* Davis et al., *supra* note 53, at 16033; Owen et al., *Residual Auditory Function*, *supra* note 53, at 290–91. The volunteers were physicians who were exposed to the sentences under anesthesia, and the fMRI scans showed that the relevant brain activations were inversely proportional to the degree of anesthesia. *See* Davis et al., *supra* note 53, at 16036.

increase their quality of life."[55] The cases of Rom Houben and Kate Bainbridge provide important examples of high-tech and low-tech devices of these types that have made a difference in the lives of some patients.

Rom Houben appeared to enter PVS as a result of a 1983 automobile crash in Belgium. After 23 years as a PVS patient, fMRI scanning results suggested Houben was conscious. Subsequently, with the help of a finger over which he had some control, Houben learned to use an interactive keyboard, with which he explained that, in fact, *he had been conscious throughout the entire period since the accident*, a span that covered more than two decades.[56]

Kate Bainbridge, following her good fortune with the face recognition task, made a significant but slow recovery, regaining a great deal of cognitive function, linguistic function, and the use of her arms.[57] She learned to use a letter board to communicate because some of her interlocutors had difficulty understanding her still imperfect speech. She has poignantly observed: "It really scares me to think what might have happened to me if I had not had the scans. They show people it was worth carrying on even though my body was unresponsive."[58]

IV. THE DIAGNOSTIC CHALLENGE

Standard PVS represents an extraordinary downgrading of normal neurological and cognitive functioning, including a complete loss of consciousness. However, the Bainbridge and Houben cases, and similar cases and experimental results, seem to show pointedly that despite the appearance of Traditional Account criteria to the contrary, some patients may nonetheless be conscious.

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[55] Sarah Boseley, *Think Tennis for Yes, Home for No: How Doctors Helped Man in Vegetative State*, GUARDIAN (Feb. 3, 2010), https://www.theguardian.com/science/2010/feb/03/vegetative-state-patient-communication.

[56] Manfred Dworschak, *'My Second Birth': Discovering Life in Vegetative Patients*, SPIEGEL ONLINE: INT'L (Nov. 25, 2009), http://www.spiegel.de/international/spiegel/my-second-birth-discovering-life-in-vegetative-patients-a-663022.html.

[57] *See* Groopman, *supra* note 35.

[58] *Id.*

This suggests that the problem of misdiagnosis may be much more challenging than previously thought.

A. *Does Consciousness Exist in the Patient?*

One might say the clinician faces a problem of existence, specifically, whether or not consciousness actually exists in the patient (the problem of existence is sometimes called the "ontological" problem). But the challenge of the clinician also concerns a problem of knowledge, specifically, how the clinician can know whether consciousness exists in the patient (the problem of knowledge is sometimes called the "epistemological" problem).

In the course of making *external* observations of patient behavior, clinicians see behavior they believe to be so abnormal that it cannot be intentional, which in turn leads to the inference that PVS patients lack consciousness entirely. The challenge of explicitly identifying the signs of such abnormality is so difficult that, while guided by the criteria in the Traditional Account,[59] it leans heavily on each clinician's intuitions. The experimental results discussed above suggest that those intuitions and patterns of inference are inadequate and problematic.[60]

Bainbridge, Houben, and similar cases demonstrate that consciousness and a normal range of mental states can still exist in PVS patients, even though the standard motor commands that the patients previously used to produce externally observable physical

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[59] MSTF I, *supra* note 6.

[60] If we label each clinician's threshold of extreme abnormality "degree D," the problematic clinical reasoning can be captured this way: (1) Any prospective PVS patient whose externally observable physical behavior appears abnormal to degree D cannot be acting intentionally, (2) Patient P's externally observable physical behavior appears to be abnormal to degree D, therefore, (3) patient P's externally observable physical behavior cannot be intentional. Further, the clinician's problematic reasoning as to the question whether the patient possesses awareness or consciousness can be captured this way: (4) Any prospective PVS patient whose externally observable physical behavior appears abnormal to degree D does not possess awareness or consciousness, (5) Patient P's externally observable physical behavior appears abnormal to degree D, therefore, (6) Patient P does not possess awareness or consciousness. The Bainbridge and Houben cases suggest that the major premises ((1) and (4)) in these inferences are false, and lead to false and misleading conclusions ((3) and (6)).

behavior have gone seriously awry. In these circumstances, clinicians who are only able to examine *external* behavior face a knowledge barrier that compels them to answer the question of existence in the negative. That is, *consciousness does not exist* in the PVS patient. But, in fact, fMRI and other technologies are now available that serve to penetrate the knowledge barrier by permitting observations of patient behavior from a different point of view. Those observations can arguably be characterized as proxies for the patient's *internal* point of view. As a result, clinicians equipped with fMRI observations may sometimes be warranted in answering the existence question in the affirmative; that is, they might reasonably conclude that *consciousness and self-awareness do likely exist to some degree* in certain PVS patients.

B. *Misdiagnosis Redux*

We noted earlier that, even in optimal circumstances, the behavior of PVS patients may be susceptible to conflicting interpretations and misdiagnoses.[61] Let's now look more closely at the process involved. To review, the diagnostic criteria of the Traditional Account are *external* in the sense that the physician primarily reviews external behavioral evidence presented by the patient. On that basis, the physician makes certain inferences as to whether the patient possesses awareness or consciousness.[62] Thus, the physician determines that the patient shows, for example, "no evidence of language comprehension or expression" and "no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli."[63] Dr. Fred Plum made the point in the following way while testifying in the Jobes case:

> [The] [v]egetative state describes a body which is functioning entirely in terms of its internal controls. It maintains temperature. It maintains heart beat and pulmonary ventilation. It maintains digestive activity. It maintains reflex activity of muscles and nerves for low level conditioned

[61] *See supra* note 36 and accompanying text.
[62] *See* Blumenfeld, *supra* note 23, at 20–21.
[63] *See supra* note 16 and accompanying text.

> responses. But there is no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner.[64]

It is especially noteworthy that even though some behavior, as described in the Traditional Account, may actually be suggestive of intentional action by the patient—such as smiling, becoming tearful, making grunting, moaning, or screaming sounds—the behavior is seen by the clinician using the Traditional Account to "misleadingly suggest" purposeful or intentional movements. Thus, the clinician, in effect, strips away intention from his or her perception of the prospective PVS patient's behavior. And then that "absence" of intention is seen as a powerful indication that the patient does not possess consciousness at all.

However, cases like Bainbridge and Houben suggest that a physician may err in stripping away hints of intention from the patient's outré behavior. In those cases, it may be that behavior such as smiling, becoming tearful, and making grunting, moaning, or screaming sounds does not "misleadingly suggest" purposeful or intentional movements, but properly suggests them.[65] This is the upshot of the insight that the patient's behavior may be susceptible to conflicting interpretations, and therefore misdiagnoses. In this sense, the behavioral evidence can support multiple, not necessarily consistent, theories.

Consider that an arm moving might be correctly interpreted in one case as an intentional act by someone with the full cognitive powers of a healthy person, but in another case, the *identical* arm movement could be correctly interpreted as a non-purposeful, random event caused by the body of a PVS patient with no cognitive powers or conventional motor control. Yet, in a third case, the identical movement could be correctly seen as the product of an intention formed by a PVS patient, whose motor command failed to execute properly due to a nervous system malfunction, even though the patient was, unbeknownst to observers, conscious to a significant degree.

Thus, the phenomenon poses something of a taxonomical mess. Some may wish to describe the extraordinary cases that have

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[64] *In re* Jobes, 529 A.2d 434, 438 (N.J. 1987).

[65] *See supra* Part III.D for a discussion on the Bainbridge and Houben cases.

concerned us above as "previously unknown high-functioning Minimally Conscious State cases" that should not have been characterized as PVS. Others may wish to call them PVS cases of a new sub-type in which consciousness has been undetectable without the aid of special tools such as fMRI. Others may think an entirely new category is warranted. The upshot for our purposes, however, is more practical: a patient diagnosed as lacking in consciousness may, in fact, possess it, and with the assistance of new methods and neuroscientific tools, such as fMRI scans and re-formulated patient examination algorithms, the clinician may succeed in avoiding a misdiagnosis and its potentially grave consequences (including the unwarranted and arguably unlawful removal of a patient from life support).

In an earnest attempt to do just that, Adrian Owen scanned his Canadian patients twice a day for three days.[66] Likewise, Steve Laureys implemented a testing procedure for his Belgian patients which features 25 patient tasks.[67] These included grasping objects and reacting to sounds, each of which patients had to successfully perform repeatedly as a way of ruling out random reflexes.[68] Further, the Belgian government has imposed a legal requirement that Steve Laureys's procedure be used in all government-run nursing homes.[69]

V. CLINICAL AND LEGAL DESCRIPTIONS

A. *Degradation, Indignity and Loss of Consciousness*

Loss of consciousness is a key quality-of-life concern in PVS cases. We closely identify consciousness with our humanity, and if we are robbed of it by PVS, we may regard our quality of life as greatly degraded, so much so that words such as "undignified" are sometimes used to characterize it. For some, but not all, the adjective "vegetative" expresses that degradation and loss of dignity. For example, Jennet and Plum thought the adjective was a neutral term with no derogatory connotations.[70] But Raphael Cohen-Almagor

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[66] Groopman, *supra* note 35.
[67] Dworschak, *supra* note 56.
[68] *Id.*
[69] *Id.*
[70] *See* Jennet & Plum, *supra* note 2.

calls it "ethically suspect," observing that "[n]o one would like to be treated as a carrot or a potato, nor would anyone like the idea that a loved one would be treated as such."[71] He adds that because "language is—to a great extent—a reality-building instrument, a warning should be raised against the use of discriminatory and demeaning terms that could cause medical personnel to disrespect patients."[72]

Against the backdrop of this debate, it is worth noting that an expert assessment by a physician that the loss of consciousness is virtually permanent can be devastating and dispositive for family and friends. Indeed, it can play a key role in the decision to withdraw life support from the PVS patient, either by Advance Directive or through instructions given by a surrogate or clinicians in a default situation. Your determination to help your loved one Lucky cling to life in the hope of regaining consciousness may be greatly weakened in the face of a physician's declaration that Lucky is almost certain to live life as nothing more than a vegetable going forward. Thus, the consequences of *mistakenly* informing family members or surrogates that there has been a permanent loss of consciousness when, in fact, consciousness may *not* have been lost permanently or at all, may be irreversible.

Of course, one wants to avoid such catastrophic outcomes by ensuring to the extent practical that physicians, caregivers, family members, attorneys, and others potentially involved in crafting Advance Directives and shaping end-of-life protocols are adequately informed of the complexities of PVS diagnosis. That is, in any specific case, one wants to take all reasonable measures to inform relevant decision makers as to recent research results and advances in technology that may shed important light on whether a patient may have suffered a perceived loss of consciousness, permanent or otherwise.

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[71] *See* Raphael Cohen-Almagor, *Language and Reality at the End of Life*, 28 J.L., MED. & ETHICS, 267, 269 (2000).

[72] *Id.* Others, too, have described the word as pejorative. *See generally* C. Machado et al., *Vegetative State is a Pejorative Term*, 31 NEUROREHABILITATION 345 (2012).

B. *Guidance for Advance Directives, Living Wills & End of Life Protocols*

The Advance Directive, and similar instruments such as the Living Will, are built on a strong belief in the idea that when the adult individual is a patient, he or she has the right, and therefore the authority, to control his or her healthcare decisions.[73] This means that treatment options are evaluated and chosen from the point of view of the patient rather than the physician or caregiver.[74] As a result, the patient is able to control and shape, in certain key respects, his or her quality of life, and make decisions in advance as to what treatment will be provided or withheld in case the patient falls into dire medical circumstances and is cognitively impaired in some specified fashion. How does the Advance Directive process work?

Advance Directives are typically signed, and sometimes drafted, by persons of sound mind, whether healthy or ill, in anticipation of health problems that may render them unconscious or otherwise unable to make authoritative decisions concerning their own medical care.[75] As we saw in Lucky's case, the document can include an instruction to take action that will, in effect, end the life of the patient under certain conditions.[76] PVS is a condition sometimes included among those that will trigger such an end-of-life instruction. Thus, an erroneous diagnosis or description of PVS, if not detected, may trigger an end-of-life instruction never intended

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[73] INFORMATION FOR PATIENTS: PATIENT RIGHTS AND RESPONSIBILITIES, UCSF MED. CTR., https://www.ucsfhealth.org/pdf/patient_rights_and_responsibilities.pdf.

[74] *See, e.g.*, Mayo Clinic Staff, *Living Wills and Advance Directives for Medical Decisions*, MAYO CLINIC (Dec. 15, 2018), https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303.

[75] *See* Patient Self-Determination Act, 42 U.S.C. § 1395cc(f) (2018).

[76] *See id.* This is commonly done indirectly in hospital settings by way of a "DNR" or "do not resuscitate" order. *See id.* The federal Patient Self-Determination Act requires certain health care institutions to take steps to educate all adult patients of their right to accept or refuse medical care. *Id.* Furthermore, the institutions must inquire on admission whether a patient has an Advance Directive ("AD"), and must maintain policies and procedures on ADs and provide information about those policies and procedures to patients when admitted. *Id.* The statute defines an AD as a "written instruction, such as a living will or durable power of attorney for health care, recognized under State law . . . and relating to the provision of such care when the individual is incapacitated." *Id.*

by the author. One generally does not want one's life to be ended mistakenly on the basis of misinformation.

For that reason, given the watershed research results we have seen above, the Advance Directive and associated practices in their present form may merit revision. When we review statues and regulations, official guidelines, model Directives, and related materials used in some states, we find some to be defective and misleading as they characterize PVS as a condition in which there is a permanent or irreversible loss of consciousness. They may not discuss recent research or mention the possibility that some PVS patients may, in fact, be found to be conscious or misdiagnosed with the help of new technology.

To illustrate this point, let's turn to various kinds of guidance provided in three states: Virginia, New Jersey, and Florida. The guidelines appear to be misleading as they do not reflect current research. For example, in its official guidance for the Advance Directive, the Commonwealth of Virginia explains the term "terminal condition" and the expression "persistent vegetative state" in the following way: "[terminal condition] means that your doctor has determined that you are likely to die soon or that you are in a *persistent vegetative state*, which is when you have no awareness of your surroundings and your doctors have determined you will not recover."[77]

These provisions may mislead the target audience because they state that a PVS patient has no awareness of his or her surroundings. Of course, that mistaken characterization of PVS does not square with the research we met above, which strongly suggests that some patients may well have such awareness.

Similarly, New Jersey's official guidance appears to be at odds with current research. This is because the guidance indicates that PVS patients cannot interact with their environment or other people: "[permanent unconsciousness is a] medical condition defined as total and irreversible loss of consciousness. The term "permanently unconscious" includes the conditions *persistent vegetative state* and

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[77] *Healthcare Decisions Day: Frequently Asked Questions*, VA. STATE BAR, http://www.vsb.org/site/public/healthcare-decisions-day (last updated Mar. 13, 2019) (emphasis added).

irreversible coma. Patients in this condition cannot interact with their surroundings or others in any way and do not experience pleasure or pain."[78] The official guidance further defines PVS as:

> [a] condition of permanent unconsciousness in which the patient loses all capacity for interaction with their environment or other people. It is usually caused by an injury to the brain. It is normally not regarded as a terminal condition and with the aid of medical care and artificial fluids and nutrition patients can survive for many years.[79]

Florida's statutory approach is similarly problematic.[80] For example, in the course of discussing the Advance Directive, Florida provides the following definition of PVS:

"'Persistent vegetative state' means a permanent and irreversible condition of unconsciousness in which there is: (a) The absence of voluntary action or cognitive behavior of any kind (b) An inability to communicate or interact purposefully with the environment."[81] On the contrary, as discussed above, it may well be possible for some PVS patients to engage in voluntary action and interact purposefully with the environment.

These rather glaring defects in Virginia, New Jersey and Florida descriptions and characterizations of PVS and related phenomena are derived from a misunderstanding of the complexities of PVS. That misunderstanding is tied conceptually to diagnostic criteria rooted in the Traditional Account, which antedate the results we have reviewed.

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[78] N.J. BIOETHICS COMM'N, ST. OF N.J. COMM'N OF LEGAL AND ETHICAL PROBLEMS IN THE DELIVERY OF HEALTH CARE, ADVANCE DIRECTIVES FOR HEALTH CARE: PLANNING AHEAD FOR IMPORTANT HEALTH CARE DECISIONS 9 (1991) (emphasis added).

[79] *Id.*

[80] *See* FLA. STAT. § 765.101 (2012).

[81] *Id.* A related provision, which concerns PVS cases in which no Advance Directive has been prepared, provides that life-prolonging procedures may be withheld or withdrawn only if "[t]he guardian and the person's attending physician, in consultation with the medical ethics committee of the facility where the patient is located, conclude that the condition is permanent and that there is no reasonable medical probability for recovery." *Id.* § 765.404.

C. *Revisions and Reforms*

In view of the research results presented above, and the prospect of further important advances as a result of evolving neuroscience technology, we strongly recommend revisions that may benefit those whose lives are affected by PVS.

First, competent state authorities should be urged to revise or amend all PVS-relevant statutes and government-based regulations and guidelines, including all sample Advance Directives, "living wills" and associated literature, so that they reflect the current state of neuroscience research. Second, all PVS-relevant literature that may be distributed to patients and family members by physicians, hospitals, hospices, insurers and other participants in the healthcare delivery system should be similarly revised. Third, such revisions and amendments should be pursued in all jurisdictions, even though as a demographic matter, some jurisdictions—such as Sunbelt and other states that host substantial retirement communities—may have much greater numbers of at-risk residents than others. Fourth, given the pace of technological change, arrangements should be made for periodic updates, and for those updates to be communicated in a timely fashion through mass mailings and electronic distributions to hospitals and other facilities where administrators, physicians, nurses and other caregivers regularly work with prospective or actual PVS patients.

VI. CONCLUSION

We have described the basics of persistent and permanent vegetative states and reviewed both the traditional clinical account used to assess such states and associated problems of misdiagnosis. We have also reviewed recent research with PVS patients that has made use of fMRI and other neuroscience technology, and produced important results. In particular, this research indicates that certain PVS patients are conscious and possess significant cognitive ability. In addition, it strongly suggests that clinicians using the traditional account may mistakenly conclude that PVS patients lack consciousness when, in fact, they do not. Such errors should be of great concern because they can lead to the removal of patients from life support, under conditions the patients never contemplated when

signing Advance Directives, and other end-of-life protocols. We believe such errors can be reduced significantly if current PVS research is widely circulated among relevant parties. We believe this can be done by amending or replacing statutes and regulations, as well as non-legal literature, commonly used to draft and interpret end-of-life protocols, and to educate and inform professionals and lay persons. We strongly suggest that such measures be undertaken without delay by competent authorities.